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**THE FAMILY PARTNERS PROJECT:
A NATIONAL SURVEY OF THE HEALTH CARE EXPERIENCES OF
FAMILIES OF CHILDREN
WITH SPECIAL HEALTH CARE NEEDS**

TECHNICAL REPORT #2:

SPECIAL ISSUES REGARDING SURVEY QUESTIONS

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The Family Partners Project was a collaborative study conducted by faculty of the Heller School, Brandeis University and national staff of Family Voices, an organization of friends and families of children with special health care needs. In 1998-1999 a national survey of over 6000 families of children with special health care needs in 20 states was conducted to investigate their experiences in accessing a variety of health and therapeutic services needed by their children. As part of the project, a survey instrument was developed that utilized standardized questions used in other related surveys as well as newly constructed questions that focused specifically on issues of concern to families of children with special health care needs. This report presents a variety of suggestions regarding the questions in the survey instrument that should be considered by others interested in using some or all of our questions.

Our experience in the analysis of the data collected in the national survey provides the basis for a variety of suggestions regarding revisions to the instrument that should be considered by others interested in using all or some of the questions we asked.

Some of the suggestions may resolve apparent confusions experienced by some or many respondents to the questions, particularly regarding skip patterns that were misunderstood or ignored. Some of the suggestions point to ways in which questions could be simplified in order to reduce respondent burden. Some of the suggestions indicate ways to sharpen the questions in order to improve the reliability and validity of the question. Finally, we identified a limited number of questions that we did not ask but wish we had.

These suggestions are just that -- suggestions. We have not field tested any alternative versions of our questions based on these suggestions. They are offered, however, to indicate those questions in the survey that were problematic from either a respondent perspective or an analysis perspective.

Questions that should be revised:

(1) *“Does your child have a health insurance plan, that is a health plan, health insurance, or Medicaid to help pay for the costs of medical care?” (Q. 10).* In some instances, respondents answered “no” but later indicated the child was covered by Medicaid (response to Q. 15). (Note: we resolved this inconsistency during the data cleaning process.) Although the question included the state-specific name of the Medicaid program in each of the 20 states in which the survey was conducted, the question may have been too complex in its construction. We suggest simplification of the question, perhaps by first asking if the child is covered by any health plan or insurance and second, asking specifically if the plan is a Medicaid plan as well as listing other possible payers of the plan.

(2) *“Is your child’s main health insurance a “managed care plan?” (Q. 19).* Over 30% of the respondents indicated they “don’t know” to this question. While this is a legitimate response and useful information, alternative approaches may need to be used to gather accurate information on the characteristics of health plans if one goal of a study is to categorize the type(s) of health plan. We included several questions that focused on specific features of the child’s health plan (i.e., requirement of a primary care provider, requirement of referrals from the primary care provider in order to receive specialized services, existence of network of providers, etc.) which we used to develop a scale of cost containment. Other approaches may be appropriate based on the specific goals of future studies.

(3) *“How is your child’s main health insurance plan doing on...” (Q. 21).* The response categories were “excellent” “good” “okay” “poor” and “don’t know”. First, we recommend using “fair” instead of “okay” in order to be clearer about the gradient of responses. Second, we recommend adding a “not applicable” response category, as some of the items listed for this question are not applicable in all plans (i.e., paying for second opinions; paying for services that are outside the plan’s network).

(4) *“Does your child have any other health insurance plan?” (Q. 29).* We strongly recommend including Medicaid as a separate response category, rather than including Medicaid with other government programs.

(5) “*For which of your child’s services does this other health insurance plan pay?*” (Q. 30). Respondents are likely to be aware of only what their child’s secondary health insurance has actually covered for their child. The question should be revised to ask what their child’s secondary plan has covered for their child in the last year (or other appropriate time frame) in order to improve the accuracy of the information and the interpretation of the results.

(6) Q. 35b asked *how many times in the last 12 months the child was seen by one or more specialists as an outpatient*. “Specialist” was not defined and could be interpreted quite broadly or narrowly by respondents, rendering the data less precise than may be needed.

(7) Q. 39, 42, 45,48, 51 asked if the respondent had “*any problems getting (type of service) your child needed*” in the last 12 months. This construction proved quite problematic because the questions are double-barreled. They ask both if their child received the service and if there were problems in accessing the service. We recommend asking these questions separately.

(8) Q. 48 asked about the *receipt of physical therapy, occupational therapy, speech therapy, and other therapies*. First, we recommend that “other therapies” either be defined specifically or provide space for the respondent to indicate what the other therapy is (are). Second, we do not recommend retaining the current construction of this question, as the respondent burden of such a complex grid was evident in both the visual inspection of the data and in the need for extensive data cleaning to yield consistent and valid responses.

(9). Q. 54 asked about *other services the child needs*. We experienced a large amount of missing data from this question, which may have resulted from the complex response categories which covered whether the child received the service or not, the satisfaction of the respondent with the received service, and whether the child did not receive the service but needed the service. We suggest simplification of the response categories, by focusing on receipt of the service first, and unmet need second. Further, we note that “genetic counseling” and “genetic testing” may be services received by others in the family rather than the child with special health care needs, and that restricting information to “the last 12 months” may be unduly restrictive.

(10) Q. 56 asked about *parental provision of health care at home*. If the respondent reported “no,” the respondent was instructed to skip to Q.59 and not to answer the subsequent two questions on how much time the respondent spends each week arranging or coordinating the child’s care and what the child’s health plan does to assist in the coordination of care. We recommend eliminating the skip instructions for Q. 56 and having all respondents reply to Q. 57 and Q. 58.

(11) Q. 67 should be revised to ask the respondent *what his/her child has received from the state “Maternal and Child Health Program for Children with Special Needs”* in order to improve the precision of the question.

(12) Q. 72 asked the respondent to provide the *number of people in the household by age category*. Many respondents checked off the age category and did not provide a number. We could not use the data and suggest that the question be revised to ask how many people live in the household (total number) and/or how many adults live in the household and how many children (under age 18) live in the household.

(13) Q. 75 asks respondents about *the extent of their agreement with four impacts they may have experienced*. We suggest that the items be revised to include a specific time frame in which these impacts may have occurred (i.e., in the last 12 months). Without a time frame specified, it is impossible to know whether these impacts occurred and have been resolved versus current issues experienced by the respondent.

(14) Q. 78 asks about the respondent’s *current employment status*. We recommend revising the criteria for full-time employment from 30 hours a week or more (for full-time) to either 35 hours a week or 40 hours a week.

Questions that could be eliminated:

Some of the questions we asked could be eliminated because they did not yield useful information or they were ambiguous. These include:

Q. 31 *“Please tell us how your child’s main health insurance plan and second plan coordinate benefits to pay for your child’s care.* This was an open-ended question that did not yield much information. Respondents typically have no direct knowledge of how multiple plans “coordinate benefits.”

Q. 37 *“Did you choose this doctor (the doctor most important to the child’s care) for your child?”* The word “choose” was ambiguous and/or respondents may not now remember the circumstances by which their child began being treated by the doctor.

Q. 38 *“How well is this doctor who is most important to your child’s care doing on...(l) communicating with my child’s other health care providers, (m) communicating with my child’s school or early intervention program, (n) communicating with other systems that provide services to my child, and (o) communicating with my child’s health insurance plan staff.* Items l, m, n, and o received a large percentage of “don’t know” responses because respondents may be unaware of the communication patterns of their child’s health providers. While for some purposes, the extent of “don’t know” responses may be instructive, users are cautioned that the question asks for information that is not typically known by respondents.

Q. 55 *“Please tell us about any other services your child needs.”* This question did not yield useful data (analytically).

Q. 77 “Please tell us about what kind of services, equipment, etc. you pay for out of your own pocket.” This question did not yield useful data (analytically).

Q. 84 “Is there anything else you want to tell us about your child’s care and health insurance plan?” This question did not yield useful data (analytically).

Questions that could be simplified:

Many of our questions had complex response categories that provided us with very valuable information and yielded a level of precision to some of the issues we were studying that was important to our study. Others may want to use a simplified version of this instrument and have information needs that are not as complex or extensive as those which guided our study. We note that the level of “respondent burden” in our study was high. While simplifying the response categories might reduce the precision of the data collected, we offer the following suggestions as possible ways to reduce the overall amount of respondent burden.

(1) Q. 10—We included the name of the Medicaid program in each of the 20 states participating in the survey. This list should be revised based on the locations in which future uses of the survey are planned.

(2) Q. 21—Items “g” and “h” do not apply in many health plans. Further, many respondents indicated “don’t know” to these items, perhaps because they had never requested a second opinion or payment for services outside their plan. These items, therefore, may be problematic in some research contexts. Items “p,” “q,” and “r” were also subject to a high level of “don’t know” responses because few plans provide these items.

(3) Q. 22-24—The response categories to these items could be simplified to yes or no if the need to know the outcome of the action is not necessary.

(4) Q-26-27—The response set to each of these questions could be simplified to a yes or no format. If only one of these questions was to be used, we recommend Q. 27.

(5) Q. 32—The response set to this question yielded information both on whether the child had a primary care provider (yes or no) and whether having a primary care provider was required by the child’s health plan. If information on the features or requirements of the child’s health plan is not germane to a future study, the response set could be simplified to a yes or no format.

(6) Q. 54—The response set could be simplified to a yes or no format regarding receipt of the listed services.

Questions we wished we had asked:

- (1) Ethnicity of the respondent. We asked the ethnicity of the child, but not of the respondent.
- (2) Special education services received by the child. We asked if the child received “specialized health services” in school (for example, OT, PT, speech therapy, nursing care, etc.) through special education or Section 504 of the Rehabilitation Act” (q. 66 c). It might be preferable to ask if the child has an Individualized Education Plan (IEP).
- (3) Primary diagnosis(es) of the child. We provided a list of 35 conditions (Q. 9), many of which were overlapping (i.e. Down syndrome, mental retardation, developmental delay). It might be preferable also to ask the respondent to indicate the child’s primary or most serious condition.
- (4) Add Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder to conditions of the child (Q. 9). Many parents wrote in this condition under “other” and we recommend that the condition be integrated into the list of conditions.

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